

Awareness and Use of Cervical Cancer Tests in a Southern Appalachian Community

THE SIGNIFICANT REDUCTION (and perhaps virtual eradication) of deaths due to cervical cancer has become a distinct possibility. With this goal in mind, cervical cancer education campaigns have been conducted throughout the nation by official and voluntary health agencies, school systems, professional associations, health care practitioners, and concerned citizens. How successful have these campaigns been? The study described was designed to provide one possible mechanism for measuring the success of such efforts to date. Data pertinent to two basic research questions were gathered: To what extent has appropriate information concerning cervical cancer detection reached people living in a relatively isolated section of America? What is the cervical cancer screening utilization record among members of this community?

Study Setting

The site of the study was Harlan County, in southeastern Kentucky, among the beautiful but geophysically isolating mountains of the southern Appalachian chain. The resurrection of the coal industry prompted by the energy crisis, the coming of the Appalachian highway system, the already discernible advance of the printed and televised word into the most distant "hollers," plus other factors, are currently at work, diminishing the sense, and the reality, of the remoteness traditionally associated with this region.

Thus, in spite of a history of isolation, today's typical Harlan Countians are not so dramatically different from

the rest of their countrymen. First and foremost, they are not the overall-wearing, straw-hatted, shoeless, jug-and rifle-toting dullard stereotypes created in the minds of many Americans by the mass media. They are not the vacant-eyed, malnourished, intellectually and emotionally dead types portrayed in many reports by so-called experts who have spent a few weeks studying these people. Nor are they the huddled family groups dressed in rags, with children in numbers that seem to defy nature, who have been photographed sitting on the porches or standing in the doorways of shacks in which other Americans would not keep their garden tools. One cannot deny, however, that in Harlan County and throughout the southern plateau a subgroup of people does exist that evidences such cultural traits and lives under conditions of deprivation the like of which cannot be found elsewhere in the United States. To deny the mountain people's presence in this area or the severity of the problems they face would be as misleading and as dishonest as to imply that this group is predominant in the area.

Medical Manpower

At the time of this study (1975), 37 physicians (1) were actively serving a county whose population, according to the 1970 U.S. census, was 37,370. Fifteen of

□ *Tearsheet requests to Dr. Andrew J. Brown, Associate Professor, Department of Health Education, Southern Illinois University, Carbondale, Ill. 62901.*

the 37 physicians were generalist-family practitioners. The 37 were distributed as follows:

Daniel Boone Clinic	24
Specialists	20
Primary care physicians	4
Solo practice (all generalist-family practitioners)	6
Private medical group (all generalist-family practitioners)	5
Clinic funded by Appalachian Region Commission (both specialists)	2

The 24 physicians housed at the Daniel Boone Clinic, an ambulatory care, multispecialty group practice, included all the county's specialists but 2 (an internist and an urologist). All four board-certified gynecologists serving the Harlan area participated in this clinic. The private medical group served the northern part of the county.

These figures suggest that Harlan County has a medical manpower problem. That problem becomes more apparent when the ratios of population to generalist-family practitioners and to selected specialists are considered. Still, the county is in a better position as to medical resources than many other southern Appalachian areas (2).

Study Methods

The Mountain Trails Health Plan, Inc., serving residents of Harlan and Bell Counties in Kentucky, provided the funding necessary for the study. This plan is a foundation-type Health Maintenance Organization (HMO) that is based administratively in Harlan, the

county seat of Harlan County. Female members of the plan between the ages of 20 and 64 residing in Harlan County formed the population (1,105 persons) from which the study sample was drawn. The lower age limit (20 years) was chosen because of the American Cancer Society's uterine cancer detection goal of a Papanicolaou test for every woman 20 years of age and over (3). The upper limit (64 years) was chosen because the Mountain Trails Health Plan was not at that time offered to the age group over 65.

Of the 1,105 female plan members 20-64 years, 837 (75.7 percent) were purchase-of-care members; the remaining 268 (24.3 percent) were full-pay members (table 1). These proportions varied somewhat from those of the overall membership, in which 78 percent were purchase-of-care members and 22 percent full-pay members.

A full-pay membership was one in which the insured person or family paid the full face value of the contract. In a purchase-of-care membership, the person's annual income had to fall below \$5,000 or the family's had to fall below \$7,000 to qualify them for premium subsidization. Funds for subsidizing the purchase-of-care memberships were provided through an Appalachian Regional Commission grant.

According to the 1970 census (4), 67.7 percent of all families in Harlan County had incomes below \$7,000. In addition, the median income for all unrelated (non-family) persons was only \$1,322. Thus, the proportion of purchase-of-care memberships to full-pay member-



ships in the Mountain Trails Health Plan was not unusual in view of the economic status of the whole community.

A randomized proportional sample of 105 women was selected for study according to two criteria—age group and the financial basis of membership in the plan (table 1). These two categories of demographic characteristics were the only ones (other than sex) that were readily available from the Mountain Trails Health Plan records. Data on educational level, marital status, number of children, previous use of cancer detection services, and other items of interest had to be gathered in the course of interviews. Stratification of the sample (table 1) was expected to yield demographic data on the population's characteristics. In table 2, selected demographic characteristics are shown both for the sample and for the general female population of Harlan County 20–64 years. Data on the Harlan County group were taken from the 1970 census report. As the footnotes to table 2 indicate, U.S. census figures frequently relate to different population parameters than those available for the Mountain Trails Health Plan sample.

The survey instrument used in the study consisted of selected questions originally developed by Dr. S. Stephen Kegeles, professor of behavioral sciences and community health, University of Connecticut School of Dental Medicine, Hartford, which were used with his permission, plus a limited number of items that I originated.

The questions from Kegeles covered such areas as demographic factors, knowledge of potential cervical cancer control through early detection, factors affecting the use of detection services, and the respondent's perception of her personal potential for experiencing cervical cancer. My own questions were designed to determine the respondent's understanding of cancer in

Table 2. Percentages of women 20–64 years with selected demographic characteristics in Harlan County population and in sample of Mountain Trails Health Plan members

Demographic characteristics	Harlan County population ¹	Mountain Trails sample ²
Age:		
20–34	32.1	28.6
35–49	33.9	27.6
50–64	34.0	43.8
Years of school completed:		
Less than 8	59.5	52.4
9 or more	40.5	47.6
Marital status:		
Single	21.3	9.5
Married	57.3	58.1
Separated	1.8	1.0
Widowed	16.4	25.7
Divorced	3.2	5.7
Employment status:		
employed	13.8	21.0
With children under 18 at home	53.1	83.8

¹ Percentages based on 1970 U.S. Census figures (reference 4). Percentages for "Years of school completed" based on all females 25 years of age and older; for "Marital status," on all females 14 years of age and older; for "Employment status," on all females 16 years of age and older; and for females "With children under 18 at home," on all families.

² Percentages based on 105 Mountain Trails Health Plan members in study sample except that percentages in the 3 age groups are based on total female members of the plan (1,105).

Table 1. Distribution of Mountain Trails Health Plan female members and of study sample of such members, by age group and type of membership

Age group	All female members of plan				Sample of female members			
	Full pay		Purchase of care		Full pay		Purchase of care	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
20–24	31	24.4	96	75.6	3	25.0	9	75.0
25–29	27	26.0	77	74.0	2	22.2	7	77.8
30–34	20	23.5	65	76.5	2	25.0	6	75.0
35–39	15	19.7	61	80.3	2	25.0	6	75.0
40–44	16	17.4	76	82.6	2	20.0	8	80.0
45–49	30	21.9	107	78.1	2	16.7	10	83.3
50–54	50	40.0	125	60.0	7	38.9	11	61.1
55–59	33	22.1	116	77.9	3	16.7	11	83.3
60–64	46	28.8	114	71.2	4	28.6	10	71.4
Total	268	24.3	837	75.7	27	25.7	78	74.3

general terms of perceptions of contagious versus hereditary implications, the relationship between age and susceptibility, and the willingness of the respondent to acknowledge personal susceptibility to cervical cancer.

A local health education aide, employed and trained by the Mountain Trails Health Plan staff, interviewed all members of the study sample in their homes. Chi-square was applied to ascertain the significance of the differences in the women's responses. The results of the statistical treatment are presented in tables 3 and 4.

Results

In recent years repeated attempts have been made to assess the cervical cytology testing experience of American women. In a study in Alameda County, Calif., in 1961 (5), 50 percent of all the women interviewed reported they had had a Papanicolaou smear test. In a similar study in San Diego, Calif., in 1964 (6), the proportion was 62 percent. Reporting on a national study of 884 women conducted by the University of Michigan in 1963, Kegeles and co-workers (6) stated that 37.8 percent of the respondents claimed they had had one or more cervical cytology tests. Writing in 1967 and reviewing the current research of that time, Kegeles (7) reported that 40 to 60 percent of the American female population had had at least one cervical cytology test and that most of these tests had been conducted during the previous few years. In a Gallup survey (8) conducted in 1970 for the American Cancer Society, 53 percent of the women interviewed said they had had a cytological test for cervical cancer.

The proportion of cervical cancer tests among the 105 Appalachian subjects in the current study is relatively high when compared with the results just cited. Eighty-one of the respondents, or 77.1 percent, claimed they had had at least one Papanicolaou test. Of these 81 women, 73 said that their test had been within the preceding 36 months. Indeed, 53.3 percent, or 56, of all the women surveyed stated they had obtained their test within the 12-month period preceding the interview.

As previously noted, the method of membership payment reflected a subject's economic status. Among full-pay members a greater percentage of women (88.9 percent) claimed to have had one or more Papanicolaou tests than among the women who were purchase-of-care members (73.1 percent). Thus, a greater frequency of previous cervical cytology screening was associated with higher income (table 3).

A considerably higher percentage of women with children reported having Papanicolaou tests than of women who had never given birth. The respective proportions—80.7 percent for women who had borne one or more children and 58.8 percent for childless women—were significantly different at the $P < 0.10$ level (table 3). Such a result is certainly not unexpected in view of the greater likelihood of the exposure of child-bearing women to cervical cancer screening.

Among married women living with their spouses, widows, and divorced respondents, the proportions having had one or more Papanicolaou smears were not very different—81.7 percent of the married living with their spouses, 78 percent of the widows, and 83.3 percent of the divorced. There was, however, a significant departure in the proportion of single (never married) subjects who had had a Papanicolaou test. Although there were only 10 single respondents, 6 indicated they had never obtained a screening test for cervical cancer (table 3).

Examination of the data by the three age categories into which the subjects were originally grouped yielded minimal variance as to Papanicolaou tests (table 3). The result of the 1970 Gallup poll (8), showing that a greater percentage of younger than older women had obtained at least one cervical cytology test, was therefore not supported. However, the study data do support the result of the earlier study by Kegeles and co-workers (6) showing that more women 30–44 years

Table 3. Papanicolaou test experience of sample of female members of Mountain Trails Health Plan, by selected demographic characteristics

Demographic characteristics	Papanicolaou test		No Papanicolaou test	
	Number	Percent	Number	Percent
Method of payment: ¹				
Purchase of care	57	73.1	21	26.9
Full pay	24	88.9	3	11.1
Childbearing status: ¹				
No children	10	58.8	7	41.2
1 or more children . . .	71	80.7	17	19.3
Marital status: ²				
Single, never married .	4	40.0	6	60.0
All other	77	81.1	18	18.9
Original age grouping: ³				
20–34	22	73.3	8	26.7
35–49	22	75.9	7	24.1
50–64	37	80.4	9	19.6
Modified age grouping: ³				
20–29	16	69.6	7	30.4
30–44	22	88.0	3	12.0
45–54	21	77.8	6	22.2
55–64	22	73.3	8	26.7
Educational level: ³				
8 years or less	41	74.5	14	25.5
9 years or more	40	80.0	10	20.0
Employment status: ³				
Employed	19	86.4	3	13.6
Not employed	62	74.7	21	25.3

¹ $P < 0.10$, > 0.05 . ² $P < 0.05$. ³ $P > 0.10$.

of age had had a Papanicolaou test than those in younger or older age groups. Within the 30-44 age group, 88.0 percent of the current study sample reported they had obtained a Papanicolaou smear test, compared with 69.6 percent of those 29 years and under, 77.8 percent of those 45-55 years, and 73.3 percent of those 55-64 years (table 3).

As the educational level increased, so did the percentage of women reporting a Papanicolaou test. Compared with respondents claiming 9 or more years of school, a smaller proportion of those indicating 8 years or less of formal education reported having had a Papanicolaou test. The variance was not, however, statistically significant.

Twenty-two of the 105 subjects in the study were employed. Examination of the 105 subjects' Papanicolaou test experience by employment status did not yield results significantly different from those that would have been expected to occur by chance. As table 3 shows, the proportion of employed women having had at least one previous Papanicolaou test (86.4 percent), however, did exceed the proportion of women who were not employed who had such a test (74.7 percent).

The relationship between a respondent's awareness of detection procedures for cervical cancer and her Papanicolaou test experience was determined through analysis of the woman's response to two questions: Are there things a person can do to help prevent or detect female cancer? and What things might a person do? Of the 81 subjects (85.2 percent) claiming to have had one or more Papanicolaou tests, 69 answered the first question affirmatively compared with 11 of the 24 (45.8 percent) with no such experience. These results were significantly different, yielding a $P < 0.001$ reading.

In response to the question as to what specific actions a woman might take to prevent or detect female (cervical) cancer, only 52.4 percent of the 105 subjects in the full sample were able to cite the taking of a specific test as one course of action. As previously noted, 77.1 percent (or 81) of all the respondents claimed that they had had at least one Papanicolaou smear test. Of these 81, however, only 49 were able to indicate the potential use of such a test. Questions to determine the subject's awareness of cervical cancer detection services preceded those related to the woman's Papanicolaou test experience. When the subject's responses to questions about previous Papanicolaou tests were negative, the interviewer would describe these testing procedures so that the subject's responses would not be affected by lack of recognition of the terminology.

No significant difference was noted between the full-pay and the purchase-of-care members in their ability to cite the taking of a specific test as a procedure for detecting cancer in women (table 4); thus, there was no income-associated difference in this ability. A discernible difference in this ability was observed,

however, in relation to the respondent's years of education. Women with 9 or more years of education demonstrated a greater awareness of Papanicolaou tests than subjects with 8 years or less. Once again, however, the difference was not statistically significant. Analysis of the results by age groups paralleled those by Papanicolaou test experience. There was little difference between the three 15-year age categories into which the respondents had been originally grouped (table 4). Compared with respondents in younger and older age groups, subjects 30-44 years of age were better able to identify the Papanicolaou test as an appropriate early detection procedure, although not significantly so (table 4). A statistically significant difference ($P < 0.05$) in Papanicolaou test awareness, however, was found between the subjects when categorized by employment status. Employed respondents evidenced a greater awareness of Papanicolaou tests (table 4).

As previously noted, married women had significantly more Papanicolaou tests than single women ($P < 0.01$).

Table 4. Papanicolaou test awareness of sample female members of Mountain Trails Health Plan, by selected demographic characteristics

Demographic characteristics	Aware of test		Not aware	
	Number	Percent	Number	Percent
Method of payment: ¹				
Purchase of care	40	51.3	38	48.7
Full pay	15	55.6	12	44.4
Childbearing status: ¹				
No children	9	52.9	8	47.1
1 or more children ..	46	52.3	42	47.7
Marital status: ¹				
Single, never married .	3	30.0	7	70.0
All other	52	54.7	43	45.3
Original age grouping: ¹				
20-34	16	53.3	14	46.7
35-49	15	51.7	14	48.3
50-64	24	52.2	22	47.8
Modified age grouping: ¹				
20-29	13	56.5	10	43.5
30-44	15	60.0	10	40.0
45-54	12	44.4	15	55.6
55-64	15	50.0	15	50.0
Educational level: ¹				
8 years or less	25	45.5	30	54.5
9 years or more	30	60.0	20	40.0
Employment status: ²				
Employed	16	72.7	6	27.3
Not employed	39	47.0	44	53.0

¹ $P > 0.10$. ² $P < 0.05$.

Yet, although knowledge of the test as a means of detecting cancer was greater among married respondents, the difference in such knowledge between these two groups was not statistically significant (table 4). Similarly, although a greater percentage of respondents with children had had Papanicolaou tests than respondents who had never given birth, greater experience with the test was not reflected in greater knowledge of it. Women without children were almost equally as aware of the test as women with children (table 4).

Discussion

A large proportion (77.1 percent) of the southern Appalachian women interviewed claimed to have had one or more previous Papanicolaou smear tests. Such a result might appear excessively high compared with the results of a number of previous studies. There are a variety of factors, however, which can be cited as affecting the differences between previous research results and those of the present study. Foremost among them are:

1. The membership of the Appalachian population sampled in a prepaid medical care plan removed the economic barriers to preventive care that are commonly faced by the more general populations surveyed in previous studies. Thus one would expect a higher percentage of women with Papanicolaou test experience in the Appalachian sample.

2. The incomes of a large percentage of the persons and families in the Appalachian medical care plan place them beyond the financial limitations set for public assistance; yet they cannot afford personal health care until they become eligible for the subsidized purchase-of-care membership. It is not unreasonable to expect an initial period of greater than normal use of health care services by such a population.

3. The cytological testing for cervical cancer of patients being seen for reasons unrelated to cancer is increasingly common. This relatively recent phenomenon appears to be adding to the number of women receiving a Papanicolaou test.

4. The fact that all four Harlan County gynecologists practice in association within the Daniel Boone Clinic, a large multispecialty group practice facility, is conducive to the systematic cervical cytology testing of women using the clinic's services for reasons unrelated to cancer detection.

5. There were no respondents in the study sample from the 65 and over age group because persons in this age group were not eligible for membership in the Mountain Trails Health Plan. Since studies of women in this older age group have repeatedly yielded low rates for cervical cytology tests, inclusion of this group would have tended to pull the percentage of the overall sample that had undergone cervical testing downwards.

6. The continued nationwide effort to inform women of the efficacy of early cytological testing for cervical cancer and to motivate action in this respect should

have increased the use of such services over the interval since completion of the previous studies.

As already reported, the amount of knowledge of the Papanicolaou test as a procedure for the early detection of cervical cancer exhibited by the respondents in the current study contrasted sharply with their Papanicolaou test experience. Only 55 respondents (52.4 percent) of the total sample and 49 of the 81 who had had Papanicolaou tests were able to demonstrate such knowledge. Thirty-two respondents who had had the test were unaware of its existence or purpose. How did this disparity arise?

Two questions must be answered in order to identify a basis for this discrepancy between knowledge and experience. First, without an awareness of the Papanicolaou test's existence, how did so many women come to experience it? One possible answer may lie in the increasing tendency among physicians to do a Papanicolaou test routinely on female patients being seen for a variety of reasons unrelated to cancer. Sansom and co-workers (9) found that 60.9 percent of 180 women in Manchester, England, who were screened for cervical cancer by their family physicians had received this test as a part of another examination.

In my sample, the high percentage of women claiming to have had such a test (77.1 percent of the total sample), and particularly the high percentage experiencing this test within the previous 12 months (53.3 percent), suggests that some positive effect is associated with this practice. Just what effect routine cervical cancer testing of patients who go to a clinic or physician for reasons unrelated to cancer detection will have upon patients' requests for subsequent repeat screenings is presently unclear.

Kegeles and co-workers (6) have expressed doubt that such an approach has the potential for increasing the repetition of cervical cancer tests periodically. My results do not refute such a conclusion, since the data needed to assess repeated periodic use were not gathered during this study. It should be noted, however, that 35.5 percent of the women in the Sansom (9) study who had been tested as part of another examination were unaware of the need to repeat the Papanicolaou test periodically.

The second question poses a somewhat different puzzle. How did so many women (39.5 percent) experience the Papanicolaou smear test without learning of its existence? One explanation appears to be that there was a failure in communication between practitioner and consumer at the point of provision of the services. Medical providers apparently have not consistently met the educational needs of the patients being screened for cervical cancer. Has the Papanicolaou test become such a routinely provided service that the patient is not informed by the practitioner of its purpose and of the need for its periodic repetition? It is difficult to imagine such a complete failure of communication between practitioner and patient, particu-

larly in view of the intensely personal nature of the practitioner's service. Rather, it is my belief that practitioners do communicate the information on cervical cancer detection, but in a manner satisfactory only to themselves and without sufficiently assessing the patient's level of comprehension. The end product of such an approach is a sizable proportion of health care consumers who have experienced a Papanicolaou test without understanding its purpose, the value of its early use, or the need for periodic repeat tests.

If this inference is valid, the doubt expressed by Kegeles and co-workers (6) as to whether routine Papanicolaou smear testing will contribute to periodic repeat tests appears to be justified.

As with much previous research related to health practices, this study was conducted retrospectively. Therefore, if a subject had undergone a Papanicolaou test, she had done so before she was interviewed for the study. In such a case it is difficult to assess cause and effect relationships. Did the subject possess an awareness of the Papanicolaou test before her screening or as a result of it? I contend that the existence of a sizable group of respondents who had had a Papanicolaou test and yet were uninformed about such tests may be primarily due to the practice of routinely conducting cervical cancer screenings of patients seeking medical care for reasons unrelated to cancer detection and to inadequate education of the patient at the time of the service.

A direct relationship cannot be established between the nationwide efforts that have been expended to inform women about cervical cancer and about tests for its detection and the patterns of awareness of cervical cancer detection and the utilization of such

services evidenced by participants in this study. Nevertheless, the study results, pertaining as they do to people living in a relatively isolated American community, suggest that considerable progress has been made in reaching the public with the cervical cancer detection message.

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SYNOPSIS

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The knowledge and use of cervical cancer screening (Papanicolaou smear test) by female members of a prepaid health plan (Health Maintenance Organization — foundation-type) based in southern Appalachia were surveyed. Of the 105 members of the plan interviewed, 81 indicated that they had experienced one or more Papanicolaou tests. This percentage (77.1 percent) was greater

than might have been expected on the basis of a review of previous research.

Factors contributing to this higher percentage were the subjects' membership in the prepaid health care plan and the increasing tendency of physicians to perform cervical cancer screening tests on patients who visit them for reasons unrelated to cancer detection. The latter phenomenon, coupled with inadequate patient education at the time of the service, is viewed as a major cause of the discrepancy found between the women's Papanicolaou test experience and their Papanicolaou test awareness. Of the 81 women in the

study reporting one or more previous cervical cancer screening tests, only 49 were able to identify a specific test for detecting cervical cancer.

Most of the results of previous research concerning the relationship of Papanicolaou test experience to age, to education, to economic, employment, and marital status, or to number of children were supported by the current study. The results of this study, conducted in a relatively isolated American community, suggest that the nationwide cervical cancer educational efforts of a multitude of agencies and individuals have met with considerable success.